Improving Coordination Between Medicaid and Title II Of The Ryan White Care Act

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Health Care Financing Administration

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EXECUTIVE SUMMARY

Human immunodeficiency virus (HIV) infection and Acquired Immune Deficiency Syndrome (AIDS) now affect all population groups, with a disproportionate impact on minorities, intravenous drug users, women, and children. Although the epidemic initially impacted large metropolitan areas, today no state, county, or community has been left untouched. One of the keys to improved access to, and delivery of, cost-effective health care services for people living with HIV/AIDS is collaboration among health care programs. This report examines how state Medicaid programs and programs under Title II of the Ryan White Comprehensive AIDS Resources Emergency Act (CARE) have coordinated more effectively and efficiently to serve populations living with HIV/AIDS.

There is considerable opportunity for the Medicaid and Title II CARE Act programs to work together to coordinate the services each program provides. The areas identified for Medicaid and CARE Act program collaboration include:

- planning and implementing home care services;
- administering drug reimbursement and assistance programs;
- administering insurance continuation programs;
- cross-training between CARE Act and Medicaid programs;
- sharing information and protecting client confidentiality;
- planning, administering, and staffing case management services;
- collaborating through CARE Act program meetings; and
- outstationing Medicaid eligibility workers.

Among the states with a high level of coordination between their Medicaid and Title II programs, several lessons to forge successful collaborative relationships emerge.

Working Relationship Prior to Title II Funding. The existence of a relationship between a state-funded HIV/AIDS program and Medicaid prior to CARE Act funding has further enhanced some states' coordination of Medicaid and Title II programs. An extensive public health network serving people with HIV/AIDS often already is in place.

Existing Programs. In states where Title II CARE Act program planning has taken into account Medicaid covered services, waiver programs, and eligibility criteria, and in states which have taken into account Title II when revising their Medicaid plans or developing waiver programs, there is an increased likelihood of successful collaboration.

Expertise. For a successful collaborative effort, the party that has the greater expertise or experience should take the lead. Among most Medicaid and Title II programs surveyed, there is a clear division of responsibility based on the expertise of each program and a willingness to trust each other in administering a joint program.

Education and Open Communication. A basic but critical need is for the staff of each program to know what services the other program provides and how these services are

administered. In states with a high degree of coordination, the Medicaid and CARE Act programs are communicating with each other at the regional, state, and county levels.

Coordination between state Medicaid and Title II CARE Act programs is important for several reasons. Coordination can minimize duplication of effort and thus save states money, expand the continuum of care available, and improve access for people with HIV/AIDS. Sharing successes and recommendations for program improvements between program counterparts is integral to meeting the complex health care needs of a vulnerable yet growing HIV/AIDS population. The examples highlighted in this report reveal that states are aware of the need for coordination and collaboration and are making progress in this area. As the staff of the Medicaid and Title II programs begin to recognize the strengths of the other, they will begin to join forces and create a comprehensive system of care for people living with HIV/AIDS.

1. INTRODUCTION

In January 1994, the Health Care Financing Administration (HCFA) contracted with the National Governors' Association (NGA) to examine how state Medicaid programs and programs under Title II of the Ryan White Comprehensive AIDS Resources Emergency Act (CARE) can coordinate more effectively and efficiently to serve individuals infected with the human immunodeficiency virus (HIV)/ Acquired Immune Deficiency Syndrome (AIDS).[1] The project addresses the concerns of state HIV/AIDS directors and health officers who were identified through a survey conducted by the Association of State and Territorial Health Officers (ASTHO). In February 1993 ASTHO released a report it prepared for the Health Resources and Services Administration (HRSA), *HIV/AIDS Technical Assistance Needs of State Health Agencies*. The report documented the need for better coordination between the Medicaid and the CARE Act Title II programs. Several of the ASTHO survey respondents suggested that clarifying several Medicaid policies would enhance the administration of both programs.[2]

The goal of the NGA project is to identify strategies that states can use to improve coordination between their Medicaid and CARE Act Title II programs. States that have developed a successful relationship between the two programs are highlighted. In addition, the barriers these states have faced in trying to foster interprogram collaboration are discussed. It is hoped that through this examination, strategies will be identified that will help other states overcome these barriers.

Ultimately, sharing successes and recommendations for program improvements between counterparts is integral to meeting the needs of a vulnerable yet growing HIV/AIDS population. To minimize duplication of effort, expand the continuum of care available, and improve access, coordination and collaboration should occur not only between the state Medicaid and CARE Act Title II offices, but also among all CARE Act grantees. Through these coordination efforts, Medicaid and CARE Act programs can collaborate in HIV service needs assessments, priority setting, and planning and evaluation activities at both the state and local levels to the benefit of all persons living with HIV/AIDS (PLWAs).[3]

Methodology

To gain a better understanding of the issues that hinder collaboration between Medicaid and CARE Act Title II programs, NGA staff first met with the staff of the Division of HIV Services in the Health Resources and Services Administration. NGA staff also interviewed the ten HCFA regional AIDS coordinators to discuss the barriers to coordination that states have identified. Moreover, specific responses from the ASTHO survey were reviewed. The Title II coordinators whose responses indicated a need for improving coordination with Medicaid were contacted to discuss their experiences in more detail, as were the survey respondents who reported successful collaboration experiences. In total, sixteen states were contacted: **Alabama**, **Arizona**, **Arkansas**, **Connecticut**, **Idaho**, **Illinois**, **Maine**, **Massachusetts**, **Montana**, **Nevada**, **New Jersey**, **North Carolina**, **Oklahoma**, **Utah**, **Washington**, and **Wisconsin**. NGA staff then surveyed a Medicaid representative from each of these states, as identified by the state's Medicaid director. Last, staff reviewed two studies recently completed by Mathematica Policy Research, Inc., for HCFA on the AIDS-related services in four states and on Medicaid home and community-based care waivers for people with AIDS or HIV infection.

Organization of Report

Background information on the AIDS epidemic, the role of Medicaid and CARE Act programs in financing and providing services to the HIV/AIDS population, and the coordination of state HIV/AIDS-related efforts prior to CARE Act funding is included in Chapter 2. A broad-brush discussion of the potential for collaboration between Medicaid and Title II CARE Act programs also is provided. In Chapters 3 through 10, state efforts to collaborate are highlighted and barriers to coordination are identified.

Despite the potential for collaboration and its promise of serving people with HIV/AIDS more effectively, state Medicaid and CARE Act program officials still have concerns about the difficulties facing this population that are unrelated to questions of coordination between the two programs. For example, patients can qualify for Medicaid only after meeting stringent financial eligibility requirements and they often cannot access affordable housing. These issues are discussed in Chapter 11. Future activities and lessons learned are described in the concluding chapter.

A table outlining the interaction between Medicaid and CARE Act programs in selected states is included in Appendix A. A list of state program contacts is found in Appendix B.

2. BACKGROUND

The condition that later would be called AIDS was first recognized by the Centers for Disease Control in 1981 through reports of a small number of cases of rare cancer and other diseases. In the early years of the epidemic, nearly 80 percent of all reported cases were from six metropolitan areas in five states—Houston, Los Angeles, Miami, Newark, New York City, and San Francisco.[4] Although the epidemic initially impacted large metropolitan areas, today no state, county, or community has been left untouched. In fact, all fifty states and the District of Columbia have reported AIDS cases to the Centers for .Disease Control and Prevention. Furthermore, though the disease once affected primarily gay or bisexual, white, middle-class men, it now affects all population groups, with a disproportionate impact on minorities, intravenous drug users, women, and children.

As the demographics of the disease change and people are living longer as a result of treatment advances, so also are the systems of financing care changing. Many of the people earlier identified as living with AIDS were from the middle class; most had private insurance as long as they were working. Medicaid primarily was a source of health care financing during the end stage of illness after these patients incurred high medical bills. However, as more minorities, women, and children have become infected, Medicaid's role in financing the services needed by these groups has also expanded. According to the 1993 ASTHO[5] report, one out of every four dollars spent on AIDS-related health care is covered by state and federal Medicaid programs.

Medicaid

Medicaid is a public insurance program designed to help pay for the health care needs of certain low-income individuals. It is a federal-state partnership; the federal government and states share the costs and states design their own programs within broad federal guidelines. States have flexibility in determining eligibility, benefits covered, providers' qualifications, and service reimbursement rates.

To receive benefits under Medicaid, low-income individuals must meet certain categorical requirements. People are automatically deemed eligible when they receive cash assistance through the Aid to Families with Dependent Children (AFDC) program or, in many states, through the Supplemental Security Income (SSI) program. To receive benefits under these so-called "categorically needy programs" and thus be eligible for Medicaid, individuals must meet the state's low-income criteria and be a member of a family with children or be aged, blind, and/or disabled. "Categorically needy programs" also include certain mandatory and optional groups of low-income children and pregnant women who do not receive cash assistance.

States may elect to provide Medicaid coverage through a "medically needy program." Under this program, people who do not meet the financial standards for cash assistance can be covered under Medicaid only if their medical costs are high enough to reduce their income to a certain medically needy income level established by the state. As of July 1994, thirty-six states had opted to operate medically needy programs.[6]

Individuals with HIV infection or AIDS can qualify for Medicaid in two ways. They may become disabled, spend down their savings, and then become eligible for either SSI or the medically needy program. Alternatively, they may qualify by meeting the usual categorical and financial tests for Medicaid eligibility regardless of their HIV/AIDS status. Medicaid eligibility in this latter case is not related to having an AIDS diagnosis nor of being HIV positive.

Ryan White CARE Act Programs

The Ryan White Comprehensive AIDS Resources Emergency Act (Public Law 101-381) was enacted August 18, 1990, "to improve the quality and availability of care for individuals and families with HIV disease."[7] The four titles of the CARE Act each serve a different purpose.

- *Title I*—Provides emergency aid to metropolitan areas with the largest number of AIDS cases. To qualify for these funds, eligible metropolitan areas (EMAs) must report more than 2,000 cumulative AIDS cases, or have a cumulative per capita prevalence rate equal to or greater than 0.0025.

- *Title II*—Enables states to provide quality health care and support services to people with HIV/AIDS and their families. Each state, the District of Columbia, Puerto Rico and certain territories are eligible for Title II CARE Act funds that are distributed according to a formula based on the number of AIDS cases reported in the state in the two most recent years, as well as the per capita income of the state relative to the national average.

- *Title III (b)*—Supports outpatient early intervention HIV/AIDS services.

- *Title IV*—Supports demonstration projects that organize and coordinate a broad range of medical, social, and support services for children, youth, women and families with HIV/AIDS, and provide enhanced access to clinical research.

Using Title II funds, state public health departments are responsible for developing a comprehensive plan for HIV/AIDS services with input from the public, including representatives of affected communities, people living with HIV/AIDS, community leaders, providers and other HIV-related state programs. States may elect to allocate Title II funds to deliver home-based health services, provide medications and other treatments, extend health insurance coverage, or to fund HIV care consortia which in turn are responsible for determining how funds will be used to coordinate a continuum of outpatient health and related support services. In 1993, states reported funding a total of 302 local and regional consortia which were providing one or more of a variety of services such as primary care, case management, mental health, dental services, home health, hospice care, and home delivered meals.

Although there are no statutory income restrictions for receiving CARE Act services, it is mandated that CARE Act programs be the payor of last resort. However, CARE Act funds can be used to pay for care provided to Medicaid recipients if the state's Medicaid program does not cover a particular service benefit, or if the recipient's service needs are greater than the amount of services available under Medicaid. For example, if a state Medicaid program does not cover in-home hospice care, a Medicaid eligible person could receive that service if available through a CARE Act-funded program. Further, if a state Medicaid plan authorizes only a certain number of home nursing visits or hours and a patient needs more, CARE Act funds may be used to pay for the additional service hours.

Coordination Prior to Title II CARE Act Funding

One way to determine whether state Medicaid and Title II programs are coordinating their efforts is to look at how well state HIV/AIDS-related efforts were coordinated with Medicaid prior to CARE Act funding. Prior to the CARE Act being authorized in 1990 and funds being

appropriated in fiscal 1991, the Health Resources and Services Administration funded a sizable HIV/AIDS services demonstration grant program from 1986 to 1990. Twenty-five cities including the first sixteen Title I CARE Act cities, received these demonstration funds. Most of the HRSA demonstration sites also received substantial Robert Wood Johnson (RWJ) funding for a minimum of four years. The RWJ and HRSA programs were designed as complementary. In 1987, HRSA funded the AIDS Drug Reimbursement Program, which provided funds to each state to pay for zidovudine (AZT) and other medications approved for treating AIDS and AIDS-related conditions. In 1990, under a demonstration home and community-based care program, additional funding from HRSA was provided on a formula basis to all states.

The experiences and successes of these programs led to the inclusion of the home care and drug reimbursement options in Title II of the CARE Act. The emphasis in the RWJ and HRSA programs on working through consortia, resulted in the planning council and consortia concepts being included in Titles I and II, respectively.

In several states, the Medicaid agency and the state's AIDS care branch (or office that handles AIDS issues for the state) were working together to create a statewide system of care for people with HIV/AIDS using HRSA and RWJ funding. For example, in **North Carolina** the heads of the two agencies worked together even prior to receiving Title II funding. The two administrators know each other well and often share the responsibility for administering their respective programs. The AIDS care branch currently is administering the Medicaid HIV case management program for people with HIV/AIDS. As a result of the collaboration, the administrators have upgraded the qualifications of the Title II-funded case managers and improved the standard of care in the entire case management program. The collaboration also has brought a higher standard of care to both of the AIDS case management programs. One program is paid for using Title II funds and the other program, for Medicaid-eligible clients, is paid for by Medicaid.

The Medicaid agency and Department of Health in **New Jersey** also had established a strong working relationship by the time Title II funds became available. The two agencies had worked together on identifying the services that should be offered under the state's AIDS home and community-based care waiver. In **Washington,** there is a very high level of coordination between the Medicaid and CARE Act programs as a result of an extensive AIDS program that was established prior to enactment of the CARE Act using demonstration grant funds awarded by HRSA and RWJ. The two programs worked together to establish a statewide system of care funded with state dollars and administered by the Department of Health, which now is the Title II grantee.

Potential for Collaboration Between Medicaid and Title II Programs

There is considerable opportunity for the Medicaid and Title II CARE Act programs to work together to effectively coordinate the services each program provides. For example, through a collaborative effort, these programs could develop a comprehensive continuum of care for persons with HIV/AIDS that includes outreach, home and community-based health care and related support services, and inpatient services when necessary. Coordination between the Medicaid and CARE Act programs can eliminate duplication of services, and thus save the state money, and ultimately serve individuals with HIV disease more effectively and efficiently.

States have identified a number of areas where there is opportunity for Medicaid and CARE Act programs to collaborate. They include the following.

- Planning and implementing home care services (e.g., Medicaid home and community-based care waivers and/or Title II statewide or consortia funded home care services).

- Administering drug reimbursement and assistance programs. (Funding may come from Medicaid, Title II, Title I, and/or state revenues.)

- Administering insurance continuation programs. (Funding may come from Medicaid, Title II, Title I, and/or state revenues.)

- Cross-training between CARE Act and Medicaid programs.

- Sharing information and protecting client confidentiality.

- Planning, administering, and staffing case management services, including Medicaid targeted case management programs, case management services included in Medicaid waiver programs, and CARE Act-funded case management services.

- Collaborating through CARE Act program meetings (e.g., Title I HIV health services planning councils, Title II statewide advisory committees, and local Title II-funded consortia meetings).

- Outstationing Medicaid eligibility workers.

The areas of collaboration discussed in the following chapters are necessarily limited by the scope of the 1993 ASTHO survey and followup interviews. While not described in this report, other opportunities for collaboration between Medicaid and Title II programs exist in areas such as establishing enhanced reimbursement rates for services as an incentive to expand access, long term care, and creation of reimbursement pools for the uninsured.

3. PLANNING AND IMPLEMENTING HOME CARE SERVICES

Medicaid programs do not typically finance the provision of home-based nonmedical social and support services that people with HIV/AIDS usually require during their illness, and may also limit the type and amount of home skilled nursing infusion therapy and hospice care available. However, the state may apply for a federal waiver in order to develop specific medical and support services in the home or in the community for individuals who otherwise would require institutionalization. Services provided under AIDS-specific waivers include but are not limited to case management, homemaker/home health aide services, personal care, adult day care, private duty nursing, and home-delivered meals. According to a report prepared for HCFA, fourteen states have Medicaid home and community-based care waivers for people with AIDS.[8]

Much opportunity exists for Medicaid and Title I and Title II programs to work together to design, develop, and operate such waiver programs.[9] In many Title I cities, as well as in communities receiving Title II consortia funds, some of the grant funds being used for home care programs could be spent on alternative care if the state had a home and community-based care waiver. Moreover, Medicaid may be able to provide a more extensive package of services through a home and community-based care waiver than what is typically available through CARE Act-funded programs, particularly in states with a low to moderate incidence of AIDS and thus a relatively small Title II CARE Act grant.

Several states have demonstrated that coordination between the Medicaid and CARE Act programs can be beneficial during the waiver submission process and for administration of a waiver for HIV/AIDS clients. Of the sixteen states surveyed by NGA, only three states—**Illinois**, **New Jersey**, and **Washington**—have approved AIDS home and community-based care waivers.

The **Illinois** Department of Public Health (the Title II grantee) and the Medicaid agency coordinated to get the state's waiver submitted and approved and to implement the program. Department staff were involved in the education of local community agencies regarding available services and referral procedures. Furthermore, the state has an interagency AIDS task force whose members include the Department of Rehabilitation Services, and the Department of Public Health. These three agencies work together to coordinate waiver and nonwaiver services. The Department of Rehabilitation Services provides the waiver services, while the Department of Public Aid runs the waiver billing through the Medicaid system so that the state can get the federal Medicaid match. The Department of Public Health provides the services that are not covered under the waiver, such as mental health services.

New Jersey was the first state to receive an "AIDS" waiver, called the AIDS Community Care Alternatives Program (ACCAP). The Department of Health and the Medicaid program collaborated to identify which services should be offered under the waiver. Because this collaboration preceded CARE Act funding, a working relationship was established early through a state-administered AIDS services demonstration grant program funded by HRSA and an AIDS services grant supported by the Robert Wood Johnson Foundation. Services provided under the waiver include, but are not limited to, case management, private duty nursing, medical day care, personal care assistance services, transitional foster care, and substance abuse treatment at home. Furthermore, like ACCAP, the Department of Health has a statewide AIDS home and community-based care program under Title II of the Ryan White CARE Act that provides services to help individuals remain in their home. Through continuous collaboration between the Department of Health and Medicaid, each time ACCAP clients reach their monthly cap on

waiver expenditures, the remaining necessary client services are paid for through the Title II home and community-based care program. The Department of Health has letters of agreement with ACCAP providers to pay for the services provided to the PLWA client until the beginning of the next month when the client goes back into ACCAP.

In **Washington**, there was a joint effort to analyze and write the application for the home and community-based waiver which currently is in its third year of operation. The Department of Health (the Title II grantee) administers two programs for Medicaid: the waiver, called CASA (Community AIDS Service Alternative) and targeted case management. The services provided under the waiver include home care, skilled nursing, psychosocial counseling, respite care, nutritional consultation, attendant care, adult day health services, transportation, and therapeutic home-delivered meals. One interesting component of Washington's waiver program is the ongoing training of CARE Act-funded case managers by the Department of Health and Medicaid on how to enroll PLWAs into the waiver program. The two programs are coordinating at the community level, which enables the programs to run smoothly.

Several other states are at various stages of applying for an AIDS home and community-based care waiver. **Arkansas** is in the early stages of estimating costs and determining the cost-effectiveness of a waiver. The Medicaid agency, the Department of Health, and numerous providers are all collaborating on the waiver application. The Medicaid and Title II programs, members of the local Title II-funded consortium, AIDS services organizations, and other service providers are doing the preliminary research to identify which services should be included in the waiver program. The state hopes to get the waiver submitted and approved in 1995. The Medicaid and CARE Act programs in **Maine** are developing a waiver request for submission to HCFA. Title II funds have been used to complete the analysis determining that the waiver program would be cost-effective. Furthermore, providers have been surveyed to identify which services should be included in the waiver. The state hopes to have the application completed by the middle of 1995.

In **North Carolina**, the Medicaid program and the AIDS care branch, which handles the Title II CARE Act funding along with other grants for AIDS services, are joining together to submit a waiver to HCFA. The AIDS care branch currently is surveying providers across the state as well as members of their consortia to identify which services are necessary for the provision of home care to PLWAs and which services will be selected for inclusion in the waiver. Once the waiver is approved, the Title II CARE Act program will be responsible for its administration.

In several states, Medicaid and CARE Act programs are forging solid working relationships not only to collaborate in the waiver application and approval processes, but also to administer the waiver program. As more state Medicaid programs rely on the expertise of Title II-funded staff in HIV/AIDS-related areas, there is increased opportunity for successful collaboration. However, though coordination helps alleviate a certain amount of the workload, it does not solve the basic problems of a cumbersome application process and burdensome paperwork.

According to the recent report *Profile of the Medicaid Home and Community-Based Care Waivers for People With AIDS or HIV Infection*[10], HCFA's Non-Institutional Long-Term Care Technical Advisory Group is working to address these administrative problems by developing a waiver prototype targeted to people living with HIV/AIDS. The main goal of this model is to promote expeditious development and approval of AIDS waiver applications. This prototype

should be a valuable resource to state Medicaid and CARE Act programs in coordinating to structure and administer home and community-based care waivers.

4. ADMINISTERING DRUG REIMBURSEMENT AND ASSISTANCE PROGRAMS

Because persons living with HIV/AIDS require expensive medication as part of their care, many states have organized drug assistance programs funded under their Title II CARE Act programs and/or other state programs. Currently, fifty state Medicaid programs cover prescription drugs and have developed billing systems to reimburse pharmacies or other providers. There is considerable latitude for state Medicaid and Title II programs to collaborate to administer a CARE Act-funded drug assistance program.

Relying on Medicaid's existing drug programs and expertise, some Title II programs have contracted with their Medicaid programs to handle medication distribution or reimbursement to low-income patients who are ineligible for Medicaid.[11] This can be done in several ways. For example, the Title II program can subcontract with the Medicaid agency to administer the program in its entirety, at no cost or for a small contracting fee. The Title II program in **New Jersey** subcontracts with Medicaid to administer its AIDS Drug Distribution Program (ADDP) as well as to facilitate the program application process, eligibility review, and reimbursement. Title II pays Medicaid an annual flat administrative fee plus a small fee for each prescription filled. The Department of Health (the Title II grantee) retains authority over, and regularly reviews the status of, new medications, the number of clients, and the rate of expenditures. The success of this program is due to the fact that it was built on an already existing, state-funded, pharmaceutical distribution program operated by Medicaid. By relying on Medicaid's expertise, New Jersey's Title II program was able to create a successful drug program for its HIV/AIDS clients.

Although smaller in scale, the Title II program in **Utah** has an internal memorandum of agreement with Medicaid to administer its drug assistance program. Medicaid manages the distribution of three HIV/AIDS-related medications (AZT, didanosine [ddI], and dideoxycytidine [ddC]), determines eligibility for the Title II-funded drug assistance program, and makes arrangements with pharmacies to obtain these medications without charging a fee. As in New Jersey, Utah chose not to create a duplicate system but to rely on the existing Medicaid program to administer the drug assistance program.

Another way state Medicaid and CARE Act programs can coordinate to administer drug reimbursement programs is by using the Medicaid eligibility verification system. State Title II and local Title I programs are able to access Medicaid eligibility information, which enables them to determine whether their clients have become eligible to receive Medicaid benefits. Once these clients are determined Medicaid-eligible, the CARE Act funds used to pay for their drug services can be used to provide medications to other low-income people with HIV/AIDS. In **Connecticut**, for example, the Medicaid program does not administer the Title II drug assistance program. However, the two programs are coordinating through the use of the Medicaid electronic eligibility verification system. The Title II program has access to Medicaid eligibility information and can verify which clients have become eligible for Medicaid benefits. Once this occurs, the client is no longer eligible for Title II-funded medication and is taken off the program. Similarly, the Title II-funded drug assistance program in **Nevada** has access to the state's Medicaid electronic verification system. This helps eliminate the possibility of both programs paying for medication for a client who is Medicaid-eligible.

The activities of other states suggest that there is opportunity for state agencies to work together to build better drug assistance programs. For example, the health plans in the **Arizona** Medicaid

program (AHCCCS) will provide clients with documentation of denial when a drug is not covered under the AHCCCS formulary. This documentation is presented to the state health department, which then supplies the medication to the client's health care provider who distributes the medication to the client. Clearly, there must be coordination among health plan staff, primary care providers, and Title II staff to ensure that clients receive the appropriate medication.

In order for any State to receive Federal matching for reimbursement of covered outpatient drugs under the Medicaid program, the drugs must be those of a manufacturer that has signed a rebate agreement with the Health Care Financing Administration on behalf of the State. Consequently, Medicaid could find that Federal matching of State expenditures for a particular, single-source AIDS-related therapy might not be available if the manufacturer has not signed such a rebate agreement. To improve access to covered medications in Idaho, Medicaid suggested that perhaps it could refer those clients with HIV/AIDS who are in need of such medications to the Title II program. By joining forces, the Medicaid and Title II programs can better serve the individuals with HIV/AIDS living in Idaho by enabling them to receive the full range of medications necessary for their care.

The **Maine** AIDS Drug Reimbursement Program (ADRP) is funded through state and Title II funds and has an agreement with the state's Medicaid program. Once an individual is determined eligible for Medicaid, the program will pay for covered services furnished to that individual up to three months prior to the date of application. Because of this Medicaid policy, the Title II program can back-bill Medicaid for prescriptions filled between the time a client applies to Medicaid and the time that client becomes Medicaid-eligible and begins receiving Medicaid benefits. Working with Medicaid, the Title II program is able to recover a considerable amount of money, which can be used to purchase medication for other people with HIV/AIDS. Similarly, once the **Connecticut** AIDS Drug Assistance Program (CADAP) determines that a client has been granted Medicaid eligibility, the claims billing unit bills Medicaid for the prescriptions covered between the date the client applies for Medicaid and the date the client is determined eligible. CADAP bills Medicaid in order to receive the 50 percent match, and the recovered funds are used against future claims for other potential clients.

Several state Medicaid programs are supporting their Title II programs in a somewhat less formal advisory capacity. For example, in **Alabama** the Medicaid and Title II programs are coordinating to ensure that CARE Act funds are only providing medications to those individuals who are unable to receive medications from other sources. To prevent duplication of services, the Title II-funded case workers must verify with Medicaid that their client is not receiving Medicaid benefits. As soon as a client qualifies for Medicaid benefits, the Title II case workers are notified and the client is removed from the drug assistance program. Similarly, Title II program staff in **Illinois** are relying on Medicaid's expertise to assist them in determining medication costs and in providing information and referrals.

Many state Medicaid and Title II programs are working together to create less expensive, more efficient drug assistance programs. Through these arrangements, the two programs are eliminating duplication of services and thus saving money, and ultimately striving to provide medication to as many individuals with HIV/AIDS as possible.

5. ADMINISTERING INSURANCE CONTINUATION PROGRAMS

People living with HIV/AIDS who are able to work often receive health insurance through their employers. However, as the disease progresses, a PLWA may become disabled and be unable to continue working. There are also individuals who lose their insurance if laid-off or fired, and due to pre-existing condition clauses, are unable to obtain coverage even if re-employed. The Consolidated Omnibus Budget Reconciliation Act (COBRA) of 1985 enabled PLWAs to extend employer-sponsored health coverage for as long as 18 months. The Omnibus Budget Reconciliation Act of 1989 enabled individuals determined disabled under Title II of the Social Security Act ("the Act") or Title XVI of the Act (i.e., the Supplemental Security Income program) to extend this coverage up to 29 months.

Group health insurance coverage for "COBRA" participants is usually more expensive than health coverage for active employees, for whom the employer generally pays a part of the premium. Therefore, it can be costly, and PLWAs may lack the necessary funds to maintain this continuation of health insurance coverage.

Title II-Funded Programs

Twenty-eight states have health insurance continuation programs, 19 of which were funded under Title II of the CARE Act in fiscal year 1993. Coverage of copayments, deductibles, prescription drugs and other family members varies from state to state. States also have different administrative structures for determining eligibility and processing payments. Some rely on Medicaid program offices (e.g., Massachusetts, Minnesota, Illinois and others). Some rely on local HIV/AIDS programs in combination with the state (e.g., California), and others use central administrative departments or outside contractors.[12] Of the sixteen states surveyed, three provided detailed information on formal coordination between their Medicaid and Title II programs in implementing a Title II CARE Act-funded insurance continuation program.

In **Illinois**, the Department of Public Health, which is the Title II grantee, and the Department of Public Aid, which houses Medicaid, cooperate to offer a special insurance program to assist PLWAs who have had to leave their jobs and will receive health insurance coverage through COBRA or other group health insurance plans. The program is administered through the Southern Illinois University School of Medicine under a three-way agreement and permits payment of monthly health insurance premiums up to a maximum of $300 to insurance companies or employers as required by the policy. Individuals are determined eligible by the Department of Public Health if they have been diagnosed with AIDS, their health insurance covers prescribed drugs, they are a resident of Illinois, and their income and assets do not exceed 200 percent of the federal poverty level. Medicaid monitors the program and provides information to permit analysis of its cost-effectiveness.

The Medicaid and Title II CARE Act programs in **Montana** have an interagency agreement to administer a Title II-funded insurance continuation program. Medicaid administers the program at no cost to Title II. The insurance premiums are paid through Medicaid's third-party liability unit using CARE Act funds. Because Montana is a low-incidence state for AIDS cases, Medicaid only paid insurance premiums for four Title II-funded clients in the past year.

The **Wisconsin** AIDS/HIV Health Insurance Premiums Subsidy Program (AHIPSP) is administered by the Department of Health and Social Services and is paid for with state and Title

II monies. This program is designed to help eligible people with HIV infection maintain their existing group health insurance when they otherwise might lose coverage because they reduce their work hours, take unpaid medical leave, or terminate employment. There are four major eligibility requirements for AHIPSP. Potential clients cannot be eligible for or receiving Medicare and must:

- live in Wisconsin;
- be covered under a group health plan offered by their employer; and
- have a family income that does not exceed 200 percent of the federal poverty guidelines.

As of June 1994, AHIPSP began to coordinate with the state's Medicaid program. Under the arrangement, AHIPSP staff are permitted to check the Medicaid eligibility database to verify whether any of their clients are receiving Medicaid benefits. If the clients are Medicaid recipients, their insurance premiums will be paid with Medicaid funds. Furthermore, Medicaid agreed to allow AHIPSP to bill the program retroactively in fiscal 1993-94 for those clients who also were Medicaid recipients.

Medicaid-Funded Programs

Under Section 1902(a) (10) (F) of Title XIX of the Act, State Medicaid programs can pay to continue health insurance for individuals, provided the cost of the "COBRA" premium is less than the cost of equivalent Medicaid coverage. These individuals may be eligible for such payments if their income is no more than 100 percent of the federal poverty level and their resources are no more than twice the Supplemental Security Income level.

Formal coordination between Medicaid and Title II CARE Act programs in implementing a Medicaid-funded insurance continuation program enables Title II CARE Act programs to be used for others purposes. Three of the States surveyed have such arrangements. The Medicaid program in **Washington** funds an insurance continuation program using state dollars. The actual administration of the program is contracted out to a nonprofit AIDS service organization. Staff from the Department of Health (the Title II grantee) collaborate with Medicaid to oversee the program. Other states' Title II programs, such as in **Alabama**, are simply relying on the Medicaid program to pay the health insurance premiums for PLWAs when it proves cost-effective. The Alabama Title II program has informed the Department of Health and other consortia members that this service is available through Medicaid and have encouraged them to help identify individuals who may be eligible to participate.

The **Massachusetts** Insurance Connection program is funded by Medicaid for people with AIDS who have incomes below 300 percent of the federal poverty level. Although 300 percent is higher than the typical income threshold for Medicaid eligibility, the program's clients meet the medical criteria and therefore Medicaid will pay the insurance premiums. Generally, clients are referred to this program by AIDS advocacy groups as well as by CARE Act-funded providers. Because the Massachusetts Title II program does not have an insurance continuation component, staff rely on the Medicaid program to serve PLWAs in the state.

PLWAs often become eligible for Medicaid by incurring high medical expenses while they are enrolled in a state- or Title II-funded health insurance continuation program. Coordination between such health insurance continuation programs and Medicaid is essential to verify Medicaid eligibility, ensure a smooth transition into Medicaid[13], and prevent the use of CARE

Act funds to pay for the insurance premiums of clients who are eligible for Medicaid coverage of their insurance premiums. Furthermore, states should be encouraged to expand their Medicaid funded-insurance continuation programs because they have proven cost-effective.

6. CROSS-TRAINING BETWEEN CARE ACT AND MEDICAID PROGRAMS

States were asked whether there are areas in which coordination efforts between their Medicaid and Ryan White programs could be improved. The responses suggest a need for improved training and education on Medicaid and Title I- and Title II-funded CARE Act programs among the staff of both programs, community-based organizations, and consortia members. Especially in metropolitan areas where Title II funds are available, this training also needs to include program managers, community-based organizations, and providers. This training ultimately should lead to increased coordination and smoother running programs.

For example, the Medicaid program in **Alabama** has an HIV/AIDS liaison who works with the Title II program to help the case managers better understand Medicaid. Medicaid has arranged training sessions to teach Title II staff which services Medicaid will pay for. The Title II program staff have indicated that these sessions are helpful, enabling administrators to stretch limited Title II funds. **Arizona** Medicaid (AHCCCS) capitates multiple acute care health plans and long-term care program contractors. Because these health care plans are located throughout the state, there is great opportunity for the individual health plans to coordinate with local CARE Act-funded providers. However, health plan staff have indicated that the agencies receiving CARE Act funds need to publicize their services so that people with HIV/AIDS can easily identify which agencies provide Title I- and Title II-funded services.

The Medicaid program in **Maine** conducted training for the HIV/AIDS case managers. Medicaid explained how Title II-funded case managers can bill Medicaid and organize their Medicaid records more efficiently. As a result of the training, clients are better served and the Title II program is running more smoothly. In addition, the case managers can call the HCFA regional offices with Medicaid questions or problems.

Massachusetts has extensive cross-training for state employees. All CARE Act-funded case managers are divided by region and trained by each agency (e.g., Medicaid and welfare). This provides the case managers with a solid background about the various social service programs offered in the state. The Medicaid program in **Nevada** is sending workers to train Title II-funded staff and staff of community-based organizations on referring Title II clients to Medicaid. The **North Carolina** AIDS Care Branch also arranges training sessions for its Title II providers. Medicaid participates in these sessions, presenting information on Medicaid eligibility.

Other states such as **Illinois** and **New Jersey** have contracted with private organizations to provide training to staff of both the Medicaid and Title II programs. The purpose of the training is to teach the case managers about the various programs available to individuals living with HIV/AIDS in the state. The Medicaid and Title II programs in **Illinois** have contracted with the Mid-West AIDS Training and Education Center to provide training and organize conferences to educate staff on an interagency level. **New Jersey** is using personnel from Rutgers University to provide training for the HIV case managers of the Medicaid and Title II programs.

Utah expressed the need to educate and formally train consortium members and providers on Medicaid eligibility. Furthermore, many of the states surveyed suggested that there should be formal training so that all CARE Act-funded staff and consortia members have a clear understanding of Medicaid and Medicaid eligibility.

States recognize the importance of cross-training the staff of various state agencies as a vehicle to improve coordination among these agencies, including the Medicaid and CARE Act programs. Training heightens awareness and provides workers with the knowledge they need to perform their jobs and serve their clients better. After training, case managers can determine which agencies provide what services and can refer clients more appropriately.

7. SHARING INFORMATION AND PROTECTING CLIENT CONFIDENTIALITY

Although training is essential to increase staff awareness, the sharing of data also provides staff with the information required to operate an effective program. Because Medicaid operates under strict privacy regulations, state Medicaid programs have difficulty releasing information to the health department unless it is directly related to the administration of the Medicaid program.

The Need for Sharing Information

In **Alabama**, the Medicaid program is unable to release specific demographics and any personal identifiers about the clients served. As a result, the Department of Health and Title II program cannot accurately assess the number of people in the state who are living with HIV/AIDS. The Department of Health would benefit from access to Medicaid client information for epidemiological purposes to cross-check the Medicaid eligibility status of people with HIV/AIDS and thus obtain a more accurate picture of the nature of the disease. In **Idaho**, an increase in information sharing could improve the overall administration of the CARE Act-funded drug assistance program. Because the CARE Act-funded program can only provide medication for those people with HIV/AIDS who are not Medicaid-eligible, it would be helpful if the Title II program could access Medicaid eligibility information on their clients. With this information, the program would be able to immediately determine when their clients begin receiving Medicaid benefits and would cease paying for their medications, thus freeing up resources for other individuals with HIV/AIDS. Furthermore, the Title II program is trying to determine the cost of providing services to individuals with HIV/AIDS for its three consortia, which received funding for the first time in fiscal 1994-95. The two programs hope to establish a way that Medicaid can share utilization data and cost information with the Title II-funded consortia program. **Illinois** respondents suggested that they would like to see the proposals and grant applications that the other state programs serving individuals with HIV/AIDS are submitting to ensure a clear understanding of all HIV/AIDS activity in the state.

In **Maine**, there is coordination between the Medicaid and Title II programs in administering a Title II drug assistance program, but there is no computer network linking together the Title II program, the Medicaid program, and the pharmaceutical companies. All the records for the program are written and filed by hand, which decreases productivity and lowers staff awareness about the other programs. An automated system to share information would enable the state to serve clients more efficiently and effectively.

Strategies for Sharing Information

In **Massachusetts**, the Medicaid and Title II programs meet periodically to update each other on the various activities of their respective programs. Recently, they have begun collaborating to share aggregate Medicaid data on the utilization of services. This information is being used by the AIDS bureau for a five-year needs assessment report on AIDS services available in the state. The needs assessment ultimately will be used to rally state resources to cover services that are not being provided by Medicaid. The sharing of information between Medicaid and Title II is possible provided that Medicaid remains an active partner in the reporting process.

Respondents from **North Carolina** also indicated that the greatest problem facing the Medicaid and Title II programs is the lack of shared information. To address this issue, Medicaid is drafting a memorandum of understanding between the two agencies, allowing Medicaid to release information to the AIDS care branch specifically concerning its case management program. Medicaid will share demographic information from the case management program such as age, sex, and the date when the client was first diagnosed with HIV/AIDS. No identifying features such as name and social security number will be shared. This information will enable the Title II program to administer its own case management program more smoothly. The Title II program will be able to determine when contact is made after an individual receives an HIV/AIDS diagnosis, and it will be able to identify the different populations of infected individuals the program is serving.

In recent months, state Medicaid and Title II CARE Act programs have begun to view each other as a resource to assist in the administration of their programs. Recognizing the need to coordinate, states are making arrangements to share valuable information. Several states have overcome the constraints in sharing information through various arrangements. Others still are grappling with this issue and are looking for solutions. Notwithstanding the need to protect the confidentiality of clients, information sharing holds much value for gauging the scope and nature of the HIV/AIDS population, reducing duplication of services, determining the utilization of services, and improving outreach.

8. PLANNING, ADMINISTERING, AND STAFFING CASE MANAGEMENT SERVICES

Although state Medicaid programs can offer case management under several different authorities, targeted case management programs can be particularly appropriate for individuals with HIV/AIDS. Targeted case management is defined under Section 1915(g) of the Social Security Act as "services which will assist individuals eligible under the plan in gaining access to needed medical, social, educational, and other services."[14] These services can be provided by states to a target population, such as persons with HIV infection or AIDS, but they require a Medicaid state plan amendment.

Several state Medicaid and Title II programs have collaborated to develop state plan amendments for targeted case management for persons with HIV infection or AIDS, and to delegate responsibility for administration of the program to Title II. The Medicaid and Title II programs in **Maine** collaborated to develop the Medicaid coverage policy for targeted case management, and in writing the regulations for the program. They also work together to increase provider reimbursement, which they hope ultimately will increase provider participation in Medicaid. The Bureau of Child and Family Services (the Title II grantee) provides the state funds for the Medicaid match.

In **North Carolina**, Medicaid worked with the AIDS care branch (the Title II grantee) to develop an HIV/AIDS targeted case management program, which began in May 1994. Administered by the AIDS care branch and funded by Medicaid, North Carolina has created a completely coordinated program. The program is targeted to Medicaid-eligible clients who have an HIV positive diagnosis, including infants who are HIV seropositive. The Medicaid and Title II programs worked together to establish the qualifications for the case managers and supervisors. They also met with consortia members and providers to identify which services should be included in the program. They hope that the HIV/AIDS targeted case management program will help get clients with HIV/AIDS into a continuum of care as soon as possible to prevent any avoidable health crises, which ultimately could increase costs. Medicaid is providing funds to pay for administrative staff at the AIDS care branch to handle the Medicaid case management and waiver programs. Medicaid staff serve as technical consultants to the program but defer to the AIDS care branch staff for the day-to-day management of the program.

Since 1988, the Medicaid and Title II programs in **Washington** have had an interagency agreement under which the Title II grantee administers the Medicaid-funded targeted case management program. Case management is one of two programs that are Medicaid-sponsored and Title II-administered; the other is the AIDS waiver.

Several state Medicaid and Title II programs have worked out arrangements to collaborate on Medicaid-funded, Title II-administered targeted case management programs. In these states, the Medicaid programs rely on the expertise of the Title II staff to create a targeted case management program that will serve their state's HIV/AIDS clients most appropriately. By working together, states can use resources more effectively and eliminate duplication of services.

9. COLLABORATING THROUGH CARE ACT PROGRAM MEETINGS

One of the authorized uses of Title II CARE Act funds is to establish and operate HIV care consortia that are designed to provide a comprehensive continuum of care to individuals with HIV disease and their families. Under the act, an HIV care consortium is defined as "an association of one or more public, and one or more nonprofit private, health care and support service providers and community-based organizations operating within areas determined by the state to be most affected by HIV disease, that agrees to use grant assistance to plan, develop, and deliver (directly or through agreements with others) comprehensive outpatient health and support services for individuals with HIV."

An important component of collaboration between the Medicaid and CARE Act programs is Medicaid representation at Title II-funded consortia meetings or other CARE Act-sponsored meetings, such as Title I planning councils. While such representation is not required under current CARE Act legislation, HRSA has encouraged Medicaid representation in these planning bodies. Generally, Medicaid representatives provide technical assistance to consortia and council members, answering questions about Medicaid and clarifying complex issues. Medicaid staff also can encourage consortia members to have clients apply for Medicaid. Other areas of collaboration might include HIV service needs assessments, priority setting, and planning and evaluation activities at both the state and local levels. Medicaid participation in these meetings can increase awareness and knowledge of existing Medicaid programs, thereby improving collaboration between the two programs.

For example, in **Alabama** the Medicaid AIDS coordinator is an active member of the HIV/AIDS planning group that administers Title II CARE Act funds and meets regularly to discuss funding priorities and other items pertaining to HIV/AIDS services in the state. Furthermore, there is Medicaid representation at consortia meetings to eliminate overlap in the services the two programs provide to people with HIV/AIDS. Medicaid representation at these meetings is crucial because it keeps communication channels open, which reduces duplication of services and ultimately saves the two programs and the state money. Medicaid works closely with Title II in an advisory capacity to ensure that the Title II program is getting the most for its money.

In **Illinois**, Medicaid staff participate in Title II consortia meetings, respond to telephone inquiries, and provide technical assistance. Furthermore, the local consortia members are encouraged to utilize the expertise of the local Medicaid staff. These meetings are important because they heighten awareness of the services the Medicaid and Title II programs offer and encourage the strengthening of state as well as local coordination. In **Nevada**, there is Medicaid representation at the consortia meetings to educate the members about the Medicaid program. Medicaid also has plans to train eligibility workers in community-based organizations regarding where to send clients if they are not eligible for Medicaid services. As knowledge of the two programs increases, the hope is that frustration and confusion will decrease. **Arizona** Medicaid (AHCCCS) program is represented at the Maricopa County Title II consortium meetings. Medicaid is a voting member and participates in decisionmaking on the allocation of Title II funds.

Fifteen of the sixteen states surveyed have consortia. (Rather than a formal consortium, **Maine** has an AIDS advisory council that acts like a consortium.) It is important to note that under the CARE Act, "states reporting 1 percent or more of the total number of AIDS cases, reported nationally, are required to use at least 50 percent of their Title II CARE funds to create and

operate consortia in those areas of the state with the largest number of individuals with HIV/AIDS disease." Twenty states and jurisdictions meet this requirement (California, Connecticut, District of Columbia, Florida, Georgia, Illinois, Louisiana, Massachusetts, Maryland, Michigan, Missouri, New Jersey, New York, North Carolina, Ohio, Pennsylvania, Puerto Rico, Texas, Virginia, Washington). An additional 22 states elect to fund consortia (Alabama, Alaska, Arizona, Arkansas, Colorado, Delaware, Hawaii, Indiana, Iowa, Minnesota, Montana, Nebraska; New Mexico, North Dakota, Oklahoma, Oregon, South Carolina, Utah, Vermont, West Virginia, Wisconsin, Wyoming).

The total number of consortia operating in 1993 was 302, or an average of more than seven for each of the 42 states. Ten states had just one statewide consortium. The largest number of consortia are in California (41), Texas (26), Massachusetts (17), New York and Georgia (16 each), Washington (14), and Florida (11).[15]

Although participation in the consortia is significant, it seems that those states that are working well at the state level also are coordinating at the local level. For example, in **Washington** Medicaid staff frequently are represented at local-level task force meetings. Several local consortia in Washington recently began holding their meetings at local department of social and health services (DSHS) and Medicaid offices. This is done to encourage local Medicaid participation and build close collaborative ties between HIV targeted case managers and local DSHS community service officers (i.e., eligibility workers). Medicaid helps the consortia members identify those services Medicaid pays for so that local planners can determine the best use for Title II consortia funds. In **New Jersey**, state and local representatives from Medicaid, Title II, and Social Security, as well as hospital discharge staff, meet regularly to discuss coordination issues.

The **Arizona**, Medicaid (AHCCCS) program is unlike traditional Medicaid programs in other states. AHCCCS provides health care via multiple acute care health plans and long-term care program contractors that are reimbursed on a prepaid, capitated basis. Local-level coordination occurs when an AHCCCS health plan case manager refers a client to a community agency that is receiving CARE Act funds in order to access needed services not covered by AHCCCS. These case managers also refer clients whose Medicaid benefits have terminated to CARE Act services so that they can continue receiving care.

One of the best methods states are using to strengthen collaboration is the participation of state Medicaid and Title II programs at local meetings. This heightens awareness at all levels and enables the staff in decisionmaking and policy positions to really understand how the two programs are or are not cooperating with each other.

10. OUTSTATIONING MEDICAID ELIGIBILITY WORKERS

Outstationing Medicaid eligibility workers in community-based provider locations helps facilitate Medicaid enrollment of PLWAs. In **Nevada**, the state welfare division places eligibility determination staff at hospitals for Medicaid enrollment purposes. Although this service is available to everyone, the eligibility staff pay special attention to people living with HIV/AIDS. Staff want to enroll PLWAs into Medicaid as quickly as possible because of the potential severity of their illness and resultant disability as well as their need for continued monitoring and treatment.

In **Maine**, there are five statewide AIDS case management agencies. Services provided at these agencies include advocacy, transportation, pre-and post-test counseling, and linkages to social service agencies serving people living with HIV/AIDS. The services provided are comprehensive, enabling individuals with HIV/AIDS to do "one-stop shopping" through tying them to a complete range of services. For example, the case managers, who are trained by Medicaid, help clients apply for Medicaid. Although the outstationing of case managers to serve people with HIV/AIDS is not occurring in every state, these examples suggest that AIDS service organizations are logical entities for connecting people with HIV/AIDS with the agencies and providers serving this population, thereby eliminating an extra trip to the Medicaid office.

11. BEYOND COLLABORATION

Two other issues have little to do with the actual coordination between Medicaid and CARE Act programs, yet they are issues that both programs have been forced to confront in serving individuals with HIV/AIDS. People with HIV/AIDS must exhaust most of their income and assets to qualify for some forms of assistance, and many are unable to access affordable housing.

The Requirement to Spend Down

As the HIV disease progresses, patients become disabled. Yet many may not meet the financial standards for cash assistance programs and thus Medicaid. In this situation, people with HIV/AIDS living in states with a medically needy program may be able to "spend down" and obtain Medicaid coverage when they incur medical bills that reduce their income to established medically needy levels. However, in doing so, these individuals and their families are impoverished. Many state officials and providers would like to avoid this situation by applying the cost of services funded by Title II to the amount needed to spend down to receive Medicaid eligibility. By doing this, more clients would become Medicaid-eligible, allowing Title II programs to maximize their funds by providing services to low-income, nondisabled individuals who are ineligible for Medicaid. However, to the extent that the patient does not have to pay for Title II-funded services, Medicaid law does not recognize the cost of the services as a cost incurred by the patient. Therefore, the cost of these services does not reduce the patient's income to the medically-needy income level, and thus this scenario is not possible.

Access to Affordable Housing

Several states mentioned that affordable housing is a major problem for people with HIV/AIDS. Because the impact of homelessness is severe on individuals whose health status already is significantly compromised by HIV/AIDS, the lack of housing may unnecessarily prolong inpatient stays, driving up the cost of care for the payor of services, whether Medicaid or the CARE Act. HIV/AIDS patients living on the street also are more likely to experience medical crises, requiring them to use costly emergency services.

Housing is not a Medicaid-reimbursed service, although states covering targeted case management for PLWAs can help them locate housing. Housing related services may be designated as a priority for the use of CARE Act funds where the Title I Planning Councils or Title II consortia have determined that critical unmet housing needs exist for low income and homeless people with HIV/AIDS, and that such needs are having a serious negative impact on the provision of outpatient primary care and/or prolonging inpatient stays. Housing related services include emergency assistance for rent/utilities, group assisted-living for late-stage and/or homeless persons, and housing referral/coordination projects. However, given the high level of unmet needs for outpatient primary health care and other related support services that CARE Act funds are intended to address, relatively few Title I and II dollars are used for housing services despite serious problems for people with HIV/AIDS. In fiscal year 1993 for example, while eighteen of the twenty-five Title I planning councils established housing as a priority, only 5.8 percent of available funds were used for that purpose.[16] That same year, approximately forty-five percent of all consortia (representing about thirty percent of the states that fund consortia), allocated a small portion of their fiscal year 1993 funds for housing related services.[17]

Some local and state governments have delegated responsibility for administering and/or disbursing funds under the Housing Opportunities for People with AIDS (HOPWA) Program to Title I and II programs respectively. The purpose of HOPWA is to provide states and localities with resources and incentives to devise long-term comprehensive strategies for meeting the housing needs of persons with HIV/AIDS and related diseases. Funds are used to enable local service providers to help prevent homelessness among persons with HIV disease.

The **New Jersey** Department of Health (the Title II grantee) wrote the state's Housing Opportunities for People With AIDS (HOPWA) program application and determines the best use of the HOPWA funds, while the state's department of community affairs administers the funds. New Jersey uses HOPWA funds for rental assistance because state officials believe that this approach enables them to serve a larger number of individuals with HIV/AIDS. Generally, the referrals to the program are made by the Title II-funded consortia and the Title I-funded service providers.

In **North Carolina**, the AIDS care branch administers HOPWA funds. The HOPWA program has contracted with the fifteen regional HIV care consortia (HIV care networks), local housing providers, and local AIDS service organizations. Furthermore, the HOPWA program contracts with five organizations to operate certified adult day care/day health care programs for people living with HIV/AIDS. Services provided by the North Carolina HOPWA program include, but are not limited to, emergency housing, support services to keep PLWAs in their homes and in new housing for people living with HIV/AIDS, predevelopment grants and loans for AIDS housing developers, and rental assistance for people living with HIV/AIDS.

12. FUTURE ACTIVITIES

In response to NGA's survey, four states—**Idaho**, **Massachusetts**, **Montana**, and **Oklahoma**—indicated that they were planning meetings between their Medicaid and Title II programs. To date Idaho and Montana, as well as other states not included in the survey such as Delaware, Florida, and Virginia, already have held meetings. The Medicaid and Title II programs in Idaho met the week of July 13, 1994, to discuss coordination issues. The Title II program staff discussed their drug assistance program, which until this year was solely funded by Title II, and both programs made a commitment to each other to increase coordination. As Idaho's Title II program just began funding three consortia this year, officials are trying to determine how much HIV/AIDS care should cost. They are hoping to work with Medicaid to obtain this information and to establish a system to share data on a regular basis.

Montana's Medicaid and Title II programs met in June 1994 to begin a dialogue on how the two programs can coordinate better. For example, they discussed the need for the local Medicaid specialists, or eligibility staff, to know enough about the Title II program so that they can refer clients for services if they are ineligible for Medicaid benefits. Medicaid also designated a staff person to serve as the HIV/AIDS liaison whom Title II staff can contact if they have questions about Medicaid billing, services for HIV/AIDS individuals, or eligibility issues. In addition, it was decided that the Title II program will assist Medicaid in analyzing service utilization costs for people with HIV/AIDS. In this case, Medicaid is relying on the Title II program's expertise as a provider of services for people with HIV/AIDS to help Medicaid determine, for example, the cost of medications and the services most often utilized.

Oklahoma indicated a need for the Medicaid and Title II programs to meet in order to discuss waivers and their potential importance in terms of services offered and resources saved.

13. LESSONS LEARNED

Among the states with a high level of coordination between their Medicaid and Title II programs, several lessons to forge successful collaborative relationships emerge.

- **Working Relationship Prior to Title II Funding.** A relationship prior to CARE Act funding explains why some states' Medicaid and Title II programs have such a high degree of coordination. An extensive public health network serving people with HIV/AIDS often already is in place. For example, in **Washington** a state-funded program called the HIV Intervention Program (HIP) that was implemented prior to Title II funding and that still exists provides care for those individuals who are not Medicaid-eligible. Furthermore, regional networks of service coordination that were established prior to the CARE Act laid the foundation for the state's Title II consortia program component. In addition to some state funds, much of the network building and establishment of HIV/AIDS services evolved from several HRSA demonstrations and RWJ-funded initiatives. The interagency coordination efforts and the integration of varied funding sources has enabled Washington to use its Title II funds more strategically to serve people with HIV/AIDS.

- **Existing Programs.** In states where Title II CARE Act programs build on already existing Medicaid programs, or vice versa, there is an increased likelihood of successful collaboration. For example, the Title II programs in **Montana** and **New Jersey** took advantage of Medicaid's existing insurance continuation program and contracted with Medicaid to administer their programs. The Title II programs did not have to spend any money to create a new program but simply had to coordinate to guarantee the success of the insurance continuation program.

- **Expertise.** For a successful collaborative effort, the party that has the greater expertise or experience should take the lead. Among most Medicaid and Title II programs surveyed, there is a clear division of responsibility based on the expertise of each program and a willingness to trust each other in administering a joint program. For example, in **North Carolina** the AIDS care branch (the Title II grantee) administers the Medicaid case management program. Because the AIDS care branch has expertise in HIV/AIDS services, Medicaid deferred to branch staff to run this program. In **Utah**, Medicaid has experience operating a drug assistance program, so the Title II program arranged for Medicaid to administer its CARE Act-funded drug program.

- **Education and Open Communication.** A basic but critical need is for the staff of each program to know what services the other program provides and how these services are administered. In states with a high degree of coordination, the Medicaid and CARE Act programs are communicating with each other at the regional, state and county levels. Staff from both programs attend state and local meetings that address health care service issues affecting people living with HIV/AIDS, and they consult with one another at the outset when planning a new program to serve this population. Where ever possible written agreements can aid the development of effective working relationships between the Medicaid agency and agencies charged with planning, administering, or providing services to Medicaid eligible individuals. These agreement should clearly identify the roles and responsibilities of each party in order to allow for the proper allocation of resources and to reduce the chance of duplication of services/effort.

- **Incidence.** Based on a limited survey of selected states, it appears that in many cases, those states with a higher incidence level of HIV/AIDS, and especially those states that are considered the "first wave states," have a higher degree of coordination than those states with a low incidence level or those that are considered second-wave states. As states were forced to grapple with coordination issues at the onset of the HIV/AIDS outbreak, state Medicaid and departments of health began working together. For example, New Jersey, which is a first-wave state, has a high level of coordination because it confronted the disease earlier than other states and had to make provisions for the HIV/AIDS individuals living in the state.

Coordination between state Medicaid and Ryan White CARE Act programs is important for several reasons. Coordination can:

- eliminate duplication of services;
- save states money because of minimized duplication;
- ensure that programs run more smoothly; and
- help serve a greater number of people with HIV/AIDS.

As the number of cases of HIV/AIDS in this country rises, smaller cities and towns are identifying ways in which they can meet the needs of these individuals. The Ryan White CARE Act was created to serve this population, distributing funds to cities and states and supporting outpatient early intervention services and clinical research on therapies for children and pregnant women. Comprehensive programs created with CARE Act funds are intended to pay for services only if there is no other source of reimbursement. Clearly, collaboration with Medicaid is important because Medicaid also serves individuals living with HIV/AIDS. Program administrators must take the initiative to begin the dialogue between the Medicaid and Title II programs on ways to coordinate services in order to benefit individuals living with HIV/AIDS in their states.

The examples highlighted in this report reveal that states are aware of the need for collaboration and are making progress in this area. As the staff of the Medicaid and Title II programs begin to recognize the strengths of the other, they will begin to join forces and create a comprehensive system of care for people living with HIV/AIDS.

Endnotes

[1] Acquired Immune Deficiency Syndrome (AIDS) is a specific group of diseases or conditions that are indicative of severe immunosupression related to infection with the human immunodeficiency virus (HIV). See U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, *HIV/AIDS Surveillance Report*, vol. 5, no. 4 (December 1993).

[2] Association of State and Territorial Health Officers, *HIV/AIDS Technical Assistance Needs of State Health Agencies* (Washington, D.C.: Association of State and Territorial Health Officers, February 1993).

[3] Throughout the remainder of this report, the acronym PLWA will be used to refer to persons living with AIDS or HIV infection.

[4] National Commission on Acquired Immune Deficiency Syndrome, *America Living With AIDS* (Washington, D.C.: National Commission on Acquired Immune Deficiency Syndrome, 1991), 11.

[5] Association of State and Territorial Health Officials.

[6] "State Coverage of Pregnant Women and Children," *MCH Update* (August 1994), National Governors' Association, Washington, D.C.

[7] U.S. Department of Health and Human Services, *Information About the Ryan White Comprehensive AIDS Resources Emergency Act of 1990* (Rockville, Md.: Bureau of Health Resources Development, August 1993), 4.

[8] Amy Klein and Craig Thornton. *Profile of the Medicaid Home and Community-Based Care Waivers for People With AIDS or HIV Infection.* (Princeton, N.J.: Mathematica Policy Research, Inc., April 1994), 6.

[9] Although home and community-based services is a component of Title I and Title II that states can opt to fund, a number of grantees instead let local and regional consortia decide whether such services are a priority. Therefore, coordination at both the state and local levels is critical.

[10] Klein and Thornton.

[11] Some Title I programs also allocate funds to their state's AIDS drug reimbursement program to help pay for treatment/medications for patients, including some of the California Title I grantees and the Title I grantees in New York City and San Juan, Puerto Rico.

[12] Hager, C., Reed, E. and Young, S. *Extending Health Insurance Coverage for Persons with HIV/AIDS*, draft article 12/94, to be published in 1995.

[13]Christine Hager, R. Baitty, and S. Young, *Characteristics of State Health Insurance Continuation Programs For Persons with HIV/AIDS* (Rockville, Md: Bureau of Health Resources Development, Office of Science and Epidemiology, Division of HIV Services, Service Documentation and Quality Assurance Branch and Technical Assistance Branch, May 1993), 7.

[14] National Governors' Association, *A Catalogue of State Medicaid Changes* (Washington, D.C.: National Governors' Association, 1989).

[15] Convisor, Richard, *State Programs Funded Through Title II of the Ryan White CARE Act, Fiscal Year 1993*, A report prepared for the Division of HIV Services, Bureau of Health Resources Development, Health Resources and Services Administration, October 1993, page 4.

[16] Division of HIV Services, Bureau of Health Resources Development (BHRD), Health Resources and Services Administration (HRSA), "Title I Spending Patterns in 1993," Staff Report, December 1994.

[17] Convisor, Richard, Ph.D., "State Programs Funded Through Title II of the Ryan White CARE Act, Fiscal Year 1993," A Report prepared for the Division of HIV Services, BHRD, HRSA, October 1993, p.5.

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Appendix A: Interaction Between Medicaid and CARE Act Programs in Selected States

		Types Of Interaction								
DHHS Region*	*State*	*Home Care Services*	*Drug Assistance Programs*	*Eligibility Verification*	*Insurance Continuation Programs*	*Cross-Training*	*Sharing Information/ Protecting Confidentiality*	*Case Management Services*	*Representation in CARE Act Program Meetings*	*Outstationing Medicaid Eligibility Workers*
IV	Alabama			X		X			X	
IX	Arizona		X						X	
VI	Arkansas	1								
I	Connecticut			X			X			
X	Idaho		X				4			
V	Illinois	X	2		X	X			X	
I	Maine	1	X			X	X	X		X
I	Massachusetts				X	X	X			
VIII	Montana				X					
IX	Nevada			X		X	X		X	X
II	New Jersey	X	X	X		X			X	
IV	North Carolina	1				X	5	X		
VI	Oklahoma									
VIII	Utah		X	X		3				
X	Washington	X			X			X	X	
V	Wisconsin				X					

Notes: * U.S. Department of Health and Human Services.

1 Preparing to apply to the Health Care Financing Administration for an AIDS home and community-based care waiver.

2 The Medicaid agency assists Title II in determining medication costs and in providing information and referrals.

3 Utah expressed the need to educate and formally train the consortium members and providers on Medicaid eligibility.

4 Medicaid and the Title II-funded consortia are trying to establish a way to share utilization and cost data.

5 Medicaid is drafting a memorandum of understanding that would allow the agency to release case management program information to the AIDS care branch (the Title II grantee).

Appendix B: State Program Contacts

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